

Senate File 548 - Enrolled

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SENATE FILE 548

AN ACT

CREATING A HEMOPHILIA ADVISORY COMMITTEE AND PROVIDING A
CONTINGENT EFFECTIVE DATE.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF IOWA:

Section 1. NEW SECTION. 135N.1 SHORT TITLE.

This chapter shall be known and may be cited as the
"Hemophilia Advisory Committee Act".

Sec. 2. NEW SECTION. 135N.2 LEGISLATIVE INTENT AND FINDINGS.

1. It is the intent of the general assembly to establish
an advisory committee to provide recommendations on
cost-effective treatment programs that enhance the quality of
life of those afflicted with hemophilia and contain the high
cost of that treatment.

2. The general assembly finds inherited hemophilia and
other bleeding and clotting disorders are devastating health
conditions that can cause serious financial, social, and
emotional hardships for patients and their families.
Hemophilia and other bleeding and clotting disorders are
incurable, so appropriate lifetime care and treatment are
necessities for maintaining optimum health. Advancements in
drug therapies are allowing individuals greater latitude in
managing their conditions, fostering independence, and
minimizing chronic complications. However, the rarity of
these disorders coupled with the delicate processes for
producing factors and administering anticoagulants makes
treating these disorders extremely costly.

Sec. 3. NEW SECTION. 135N.3 ESTABLISHMENT AND DUTIES OF HEMOPHILIA ADVISORY COMMITTEE.

1. The director of the department of public health shall
establish an advisory committee known as the hemophilia
advisory committee.

2. The committee shall review and make recommendations to
the director concerning but not limited to the following:
a. Proposed legislative or administrative changes to
policies and programs that are integral to the health and
wellness of individuals with hemophilia and other bleeding and
clotting disorders.

b. Standards of care and treatment for persons living with
hemophilia and other bleeding and clotting disorders.

c. The development of community-based initiatives to
increase awareness of care and treatment for persons living
with hemophilia and other bleeding and clotting disorders.

d. Facilitating communication and cooperation between
persons with hemophilia and other bleeding and clotting
disorders.

Sec. 4. NEW SECTION. 135N.4 MEMBERSHIP.

1. The following persons shall serve as nonvoting members
of the committee:

a. The director of public health or a designee.

b. The director of the department of human services or a
designee.

c. The commissioner of insurance or a designee.

2. The following voting members shall be appointed by the
director, serving three-year terms:

a. One member who is a board-certified physician licensed,
practicing, and currently treating individuals with hemophilia
or other bleeding and clotting disorders.

b. One member who is a nurse licensed, practicing, and
currently treating individuals with hemophilia or other
bleeding and clotting disorders.

c. One member who is a social worker licensed, practicing,
and currently treating individuals with hemophilia or other
bleeding and clotting disorders.

d. One member who is a representative of a
federally-funded hemophilia treatment center.

e. One member who is a representative of an organization
established under the Iowa insurance code for the purpose of
providing health insurance.

3 4 f. One member who is a representative of a voluntary
3 5 health organization who currently services the hemophilia and
3 6 other bleeding and clotting disorders community.
3 7 g. One member who is a patient, or caregiver of a patient,
3 8 with hemophilia.
3 9 h. One member who is a patient, or caregiver of a patient,
3 10 with a bleeding disorder other than hemophilia.
3 11 i. One member who is a patient, or caregiver of a patient,
3 12 with a clotting disorder.

3 13 3. At least one of the appointments made pursuant to
3 14 subsection 2, paragraphs "g", "h", and "i" shall be a patient
3 15 with hemophilia, a bleeding disorder that is not hemophilia,
3 16 or a clotting disorder. The committee appointments may be
3 17 made notwithstanding sections 69.16 and 69.16A.

3 18 4. If there is a vacancy on the committee, such position
3 19 shall be filled in the same manner as the original
3 20 appointment.

3 21 Sec. 5. NEW SECTION. 135N.5 MEETINGS.

3 22 1. The committee shall meet no less than four times per
3 23 year and is subject to chapters 20 and 21 relating to open
3 24 meetings and public records.

3 25 2. Members of the committee shall receive no compensation,
3 26 but may be reimbursed for actual expenses incurred in the
3 27 carrying out of their duties.

3 28 Sec. 6. NEW SECTION. 135N.6 REPORT REQUIRED.

3 29 The committee shall, by January 15, 2008, and annually
3 30 thereafter, submit to the governor and the general assembly a
3 31 report with recommendations for maintaining and improving
3 32 access to care for individuals with hemophilia and other
3 33 bleeding and clotting disorders. Subsequent annual reports
3 34 shall report on the status of implementing the recommendations
3 35 as proposed by the committee and on any state and national
4 1 activities with regard to hemophilia and other bleeding and
4 2 clotting disorders.

4 3 Sec. 7. CONTINGENT EFFECTIVE DATE. This Act, being deemed
4 4 of immediate importance, takes effect upon enactment only if
4 5 an appropriation is made for the purposes of this Act.

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4 10 JOHN P. KIBBIE
4 11 President of the Senate

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4 15 PATRICK J. MURPHY
4 16 Speaker of the House

4 17 I hereby certify that this bill originated in the Senate and
4 18 is known as Senate File 548, Eighty-second General Assembly.

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4 23 MICHAEL E. MARSHALL
4 24 Secretary of the Senate

4 25 Approved _____, 2007

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4 29 CHESTER J. CULVER
Governor